

# Patient Reported Measures Research Collaborative



Commission  
on Excellence  
and Innovation  
in Health.



## Patient Reported Measures Research Symposium

*Using patient-reported measures to improve health care for culturally and linguistically diverse (CALD) populations, People living with a Disability and First Nations peoples*

**14 November 2022**

**SAHMRI Auditorium & via Zoom (link sent via calendar invite)**

## Acknowledgement of Country

*We acknowledge this land that we meet on today is the traditional lands for the Kurna people and that we respect their spiritual relationship with their country. We also acknowledge the Kurna people as the custodians of the Adelaide region and that their cultural and heritage beliefs are still as important to the living Kurna people today. We also pay respects to the cultural authority of Aboriginal people attending from other areas of South Australia and Australia.*

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## Key Note Speaker

### Mohammad Al-Khafaji

*Mohammad Al-Khafaji is the CEO of the Federation of Ethnic Communities' Councils of Australia (FECCA), the peak national body representing Australians from culturally and linguistically diverse (CALD) backgrounds.*

*Born in Iraq, Mohammad came to Australia in 2003, via Syria. Mohammad lived in Iran and Syria and speaks Arabic and Farsi. He completed a Bachelor of Software Engineering at the University of Adelaide in 2012.*

*Mohammad's personal experiences as a former refugee from Iraq and as a migrant also mean he can uniquely relate to so many issues facing multicultural communities.*

*In addition to his experience working with numerous multicultural groups and on many community boards, Mohammad worked for several years in the corporate sector. He has also served on the SBS Community Advisory Committee and the AdStandards community panel and is a member of the CALD Health Advisory Group on COVID-19 and the Health Performance Council of South Australia, advising the Commonwealth and State governments.*

*Through his refugee journey to Australia, Mohammad has become passionate about the success of Australia's Multiculturalism. He brings a wealth of knowledge and experience to his role with FECCA.*

*Mohammad believes cultural diversity makes us richer as a society and he is passionate about ensuring the voices of new and emerging communities are heard and are represented.*



## November 2022 Presenters

### Rachel Milte

*Rachel Milte is Matthew Flinders Senior Research Fellow in Health and Social Care Economics at the Caring Futures Institute Flinders University. Dr Milte is an Mid-Career Researcher with a growing national and emerging international reputation in innovative health services research. She is currently leading the economic evaluation component of 10 NHMRC/MRFF-funded clinical trials. Additionally she has experience in assessing the views and preferences of older people and the general population for the quality of care and funding of Australia's aged care system, and in the design, development and use of person-Dr reported outcome measures with people living with dementia and their family members, including the Quality of Life Aged Care (QOL-ACC) instrument, which was designed from the ground up with people using aged care services*



### Chris Nelson

*Chris is committed to positively impacting Australia's health system. Combining extensive clinical experience in both public and private health services throughout Australia with high level change management expertise, Chris thrives on tackling complex problems facing health services. In his role as Senior Service Manager, SA Intellectual Disability Health Service (SAIDHS), Chris is dedicated to improving health outcomes for South Australians with an intellectual disability and working with health leaders to design inclusive services which collaborate to deliver exceptional*



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## Claire Hutchinson

*Dr Claire Hutchinson is a Senior Research Fellow in the Health and Social Care Economics Group at the Caring Futures Institute, College of Nursing and Health Sciences, Flinders University. She has a PhD in psychology and a background in organisational consultancy and project management.*

*Since gaining her PhD in 2016, Dr Hutchinson has been working as a mixed methods social scientist conducting research in ageing and disability. Her research focuses primarily on consumers' service preferences, outcome measurement - especially quality of life, and social return on investment. She has spent the last three years project managing an ARC Linkage project to develop a new quality of life instrument with aged care consumers for quality assessment and economic evaluation. This instrument has recently been taken up by the Department of Health and Aged Care for the new quality indicators program in aged care. Thanks to a grant from the Australian Association of Gerontology (Hal Kendig ECR Award) she has been able to extend this work into culturally and linguistically diverse communities.*



## Apoorva Kulkarni

*Apoorva Kulkarni (BDS, MPH), currently works with the Epidemiology and Outbreak Support Team at COVID Operations. In 2019, she came to Adelaide to study Master of Public Health at The University of Adelaide, during her last semester she completed her placement with Sonder, where she took up a project that involved reviewing Sonder PRMS for the CALD community. As a Public Health Officer, she has worked within several teams (epidemiology, community engagement & outbreak response teams) and has also been on rural deployment to coordinate COVID-19 outbreak response on ground. She is extremely keen to keep moving forward and explore the field of public health to see what it has to offer. Her current interests in the field of public health are health promotion and global and community health.*



## Dr Kate Smith

*Dr Kate Smith is Research Lead at the Centre for Aboriginal Medical and Dental Health, University of Western Australia, Occupational therapist and Co-lead of the Good Spirit Good Life Centre for Research Excellence based in Noongar Country. Kate has led national Aboriginal ageing well research for 20 years, co-designing assessment tools, programs and integrated care models for older Aboriginal people.*



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## Collaborative Grant Winners

### Andrew Knox

*Andrew Knox, 73, became known as the representative for families of those under-dosed in their 2014 AML chemotherapy treatment. Having relapsed, in 2017 he underwent an allogeneic stem cell transplant at the Olivia Newton John Centre and is now under the care of a broad team at the RAH. He continues to advocate for the adverse event patient safety system's reform. Knox commenced a diverse career at the Royal Military College, Duntroon, in 1967 and transitioned to industrial relations, first at the SA Public Service Board and then with CSIRO during which time he completed a major in psychology at the University of Adelaide. Aged 23, he became the first industrial relations manager of Myer SA Stores and soon after head of Human Resources for multinational tyre manufacturer Uniroyal's Australian operations. While at Uniroyal he switched focus to marketing, working for a time with renowned furniture designer, Grant Featherstone. In 1978, then a Director of international advertising agency Young & Rubicam, he was responsible for the launch of the Chrysler Sigma and then established his own accredited advertising agency, advising blue chip companies from his Adelaide offices. In 2005, in addition to other business activities, Knox returned to industrial relations then as an independent registered industrial advocate appearing before industrial courts and tribunals and continues to do so as his health allows.*



### Nicole Loft

*Nicole Loft is a Haematology Nurse Practitioner at the Royal Adelaide Hospital, CALHN. With over 15 years of haematology nursing experience, her role focuses on supporting allogeneic transplant recipients including assessment and management of graft versus host disease. Nicole is passionate about nursing leadership, research, and evidence based practice. Nicole is chair of the South Australia Nurse Group for the Haematology Society of South Australia and New Zealand, co-chairs the Cancer Nurse Research and evidence Based Practice Group at CALHN, and is a representative for the SA Health Cancer Drugs Committee. Nicole is honoured to be a finalist for the SA Health 2022 Young Professional of the Year award.*



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## November 2022 Symposium Program (ACDT)

### WELCOME

08:30	Arrival / Registration	
09:00	Acknowledgement of Country Welcome and Introduction	<b>Ecushla Linedale</b> Program Manager, Health Translation SA
09:10	Opening Address	<b>Wendy Keech</b> CEO, Health Translation SA
09:25	Statewide PRM Program	<b>Megan Scott</b> Director, PRM Program Commission on Excellence and Innovation in Health

### PRESENTATIONS

09:45	Overview of CALD engagement challenges within the healthcare and research sectors	<b>Mohammad Al-Khafaji</b> Keynote speaker
10:05	Scoping review: Visual and Adapted quality-of-life instruments for adults	<b>Rachel Milte</b>

### MORNING TEA: 10:25 am – 10:50 am

10:55	Aspects of quality of life that are most important to CALD older adults accessing aged care	<b>Claire Hutchinson</b>
11:15	The reliability and appropriateness of the Sonder Client Experience Survey for use amongst CALD consumers	<b>Apoorva Kulkarni</b>

### PRESENTATIONS

11:35	Developing and implementing a PREMs measure for adults with intellectual disability	<b>Chris Nelson</b>
11:55	Development and utilisation of the <i>Good Spirit, Good Life</i> tool	<b>Kate Smith</b>
12:15	Building a bridge between patient experiences and clinical knowledge	<b>Andrew Knox and Nicole Loft</b> Competitive Research Collaborative Grant winner

### LUNCH: 12:35 pm – 13:10 pm

### PANEL

13:15	Consumer introductions Panel and workshop summary	<b>Megan Scott</b>
13:30	Panel topic: Engaging with underrepresented populations in health programs and research	<b>Wendy Keech, facilitator</b>

### WORKSHOP

14:00	Small group discussions, providing an opportunity to reflect with consumer representatives and share insights	<b>Consumer Co-Chairs</b>
15:00	Group Summaries	
15:25	Summary of the day Evaluation	<b>Ecushla Linedale, Megan Scott</b>
15:30	Close	